

UNITED STATES DISTRICT COURT
EASTERN DISTRICT OF NEW YORK

LIZA ENGESSER, MARISOL GETCHUIS,
GEETANJALI SEEPERSAUD by her Next Friend
SAVITRI SEEPERSAUD, and MARIA JAIME on
her own behalf and as Next Friend to Y.P.S. AND
C.P., individually and on behalf of all persons
similarly situated, BROOKLYN CENTER FOR
INDEPENDENCE OF THE DISABLED, and
REGIONAL CENTER FOR INDEPENDENT
LIVING,

Plaintiffs,

v.

JAMES V. MCDONALD, as Commissioner of the
New York State Department of Health,

Defendant.

25-CV-1689

**SUPPLEMENTAL
DECLARATION OF
BROOKE ERICKSON,
VICE PRESIDENT OF
DIRECT SERVICES AT THE
REGIONAL CENTER FOR
INDEPENDENT LIVING**

Brooke Erickson hereby declares under penalty of perjury that:

1. I am Vice President of Direct Services at the Regional Center for Independent Living (RCIL), a named plaintiff in this action.
2. I make this supplemental declaration in further support of Plaintiffs' Motion for a Preliminary Injunction.
3. RCIL has been inundated with calls yesterday (April 1st) and today (April 2nd) from RCIL members with disabilities and consumers who rely on CDPAP services to remain safely in their homes rather than being confined to institutions.
4. Our members continue to report all the barriers to PPL enrollment that I described in my first declaration, which was filed as ECF #11 in support of Plaintiffs' Motion for a Temporary Restraining Order and Preliminary Injunction in *Engesser et al v. McDonald*, 25-CV-1689.

5. In addition to all those problems, on the morning of April 1st, we received a flood of calls from RCIL members, other consumers, and their personal assistants who were unable to log into the PPL system.
6. For example, RCIL member S.S. notified us that the PPL app indicated that she did not have an authorization in the system. Prior to April 1st, S.S. understood that she was authorized for services because Monroe County told her they sent the authorization to PPL. However, the PPL system did not allow S.S.'s personal assistant to clock in on PPL's system; it said that S.S. did not have an authorization in PPL's system. S.S.'s personal assistant was able to clock in using her former FI's system, Maxim. However, S.S. received a voicemail from Maxim at 10:21 AM instructing her to remind her personal assistant not to clock in with Maxim, because her personal assistant is no longer working for Maxim and would not be paid. The message also informed S.S. that workers clocking in with Maxim would "create a mess." As of 9:35 AM today, April 2nd, S.S. does not have a service authorization on file with PPL, and there is no system which will allow her personal assistant to get paid.
7. Based on the phone calls RCIL received, this problem with PPL missing authorizations was widespread.
8. Our CEO reported to the New York Association on Independent Living Centers that "We are getting a lot of calls from consumers who cannot clock in with PPL because their attendants are not fully registered, or they do not have an authorization in PPL's system. I understood the TRO as being intended to protect them from gaps in service. PPL seems to be interpreting this differently."
9. Shortly after that, an ILC facilitator reported that they could not find a single authorization for their consumers, and that they were being flooded with calls. Another ILC facilitator noted that the percent of their consumers with an authorization was 1%. A third ILC facilitator shared that "one of our Consumers who was actually able to get through to PPL was told their 'system is down' and they were being slammed with calls."

10. RCIL members also experienced other problems with the PPL's Time4Care system on April 1st and 2nd.
11. For example, we received a screenshot taken by a Spanish speaking personal assistant whose Time4Care screen had a notice in a language other than Spanish. None of us recognize the language. The individual needed to accept the notice in order to move forward in the app, despite the fact that she had no idea what she was agreeing to.
12. Similarly, later in the day, RCIL received numerous calls and messages from RCIL members reporting that their workers were now able to clock in with PPL, but they were required to sign a disclaimer acknowledging that they were not employees of PPL. This disclaimer further required workers to agree that they would not be employed until the hiring process was complete and therefore would not be paid or covered by workers' compensation or other employment protections. Further, the disclaimer required workers to accept that they might not be retroactively paid for any time entered into the PPL system if their employment was not finalized before April 30th. These workers were very upset because many of them have been calling, emailing, and submitting documents to PPL for weeks or months in an attempt to register, but have been unable to reach PPL. They do not know how they can complete this process by April 30th and are unable to work without pay or workers' compensation until that time.
13. We do not know what to tell RCIL members or their personal assistants about how they should reach PPL to finalize their registrations, or how their workers can be paid and protected by workers compensation in the meantime.
14. Given that there are over 225,000 CDPAP consumers in New York State who should be receiving CDPAP services, the fact that the State is reporting that only 65,000 workers recorded hours in the PPL system on April 1st clearly demonstrates that many of our members are suffering suspensions of essential Medicaid-funded services.
15. RCIL is preparing to distribute a "Survival Guide" with instructions for CDPAP consumers about how to use social admissions to hospital emergency rooms as a way to meet their need

for personal assistance services when their services are suspended. We are instructing our members about what to bring to the hospital, and drafting letters that they can present to emergency room staff to explain the situation and Disabled individuals' rights to remain in the community to avoid unwanted institutionalization.

16. We drafted this guide last weekend, but we believed that the TRO would protect our members from gaps in services. However, due to the state's extremely narrow interpretation of the TRO, managed care organizations are informing people that they will not pay for services. Similarly, some fiscal intermediaries are not allowing workers to clock in and get paid.
17. This is an absolute crisis.
18. RCIL continues to be extremely concerned about the health and safety of our members will suffer serious and irreparable harms, both to their health and their ability to remain in the community as opposed to being involuntarily institutionalized, when they lose essential services provided by their CDPAP assistants.

Dated: 4/2/2025
Rochester, New York

Brooke J. Erickson
Brooke Erickson



HOW TO GET THE ASSISTANCE YOU NEED WHEN YOU DON'T HAVE CDPAP PERSONAL ASSISTANTS

BACKGROUND

The Governor and state legislators have held firm on a deadline which ends all contracts with existing fiscal intermediaries in the Consumer Directed Personal Assistance Program (CDPAP) on March 31, 2025. It is unclear how many Disabled individuals and how many of their attendants are enrolled. Unless a court intercedes, it will be illegal for entities other than Public Partnerships, LLC (PPL) to serve as a Medicaid fiscal intermediary in New York State on April 1, 2025.

Policy makers erroneously believe that family and friends will continue to provide personal assistance – even if they don't get paid. As Disabled people who use the program, we know that this may be true for some people, but others truly depend on the paid CDPAP Personal Assistants – who were not family or friends – to maintain their health, safety, and freedom. Attendants – including family and friends – may not be able to wait weeks to get paid or may not trust that a large out-of-state corporation will pay them.

In response to this, the Disability Community has taken three approaches:

1. Educate and enroll CDPAP consumers and their workers as quickly as possible;
2. Advocate for an extension of the deadline to give Disabled people more time to transition; and
3. Prepare to meet the needs of Disabled people who are unable to transition in time.

This guide assumes that the first two strategies have failed is intended for Disabled individuals who have gaps in their personal assistance services. It provides suggestions on how to use a hospital emergency room to fill these gaps. This is called a social admission.

DEFINING A SOCIAL ADMISSION

A social admission to a hospital is when a person is admitted to the hospital – not for acute medical reasons – but due to **social factors** that make it unsafe or inappropriate for them to remain at home or in their current living situation.

These admissions typically involve:

- Elderly individuals who may be living alone and unable to care for themselves;
- Individuals with cognitive impairments, like dementia who are at risk without supervision and don't have the services they need;
- Lack of support systems, such as having no family or caregivers available;
- Unsafe housing conditions or homelessness;
- Awaiting placement in a nursing facility, rehab facility, or social services housing; and
- People who use CDPAP services that have ended abruptly.

Although an individual may not have an acute medical issue requiring hospitalization, they are admitted temporarily while proper social support or placement is arranged. Hospitals generally try to “minimize” social admissions. They have a limited capacity and need to meet the emergency and acute healthcare needs of people. Using hospital beds for other purposes limits the hospital's capacity to effectively serve other people. Frankly, hospitals are also concerned about payment and the cost of providing this support as well.

ASSESSING YOUR RISK

Start by identifying any gaps in your personal assistance. It has been difficult to get accurate or timely information from PPL, so a lot of people still have questions about whether their workers are “payroll ready” or will be willing and able to work on or after April 1, 2025. Your worker may not be able to go without pay for up to five or six weeks. It is imperative that you have a frank conversation with your workers, recognizing that this is potentially a difficult conversation for everyone. It is better to have an honest answer from your attendant or personal assistant than an answer that may make you feel good right now but leave you unprepared later.

Your attendants may be able to cover some of your hours for a specific period of time. You need to understand the situation. A good approach is to ask specific,

factual questions focused on the worker's ability to assist you during any gap in payment, such as asking "I understand that you aren't enrolled and payroll ready with PPL, how long are you able to continue working for me like this? This information will help me plan for my needs."

Let them know you understand their situation, "I understand that you may feel bad about this, but EVERYONE has bills they have to pay."

It is important to realize the Governor, the state legislature and, Department of Health state bureaucrats put you in this position.

Then you need to consider your specific needs and potential risks. We all have different medical conditions and needs. Obviously, someone who uses a ventilator may be at serious risk even if there is a short gap in services. If you are able to manage on your own, but won't have someone to help you transfer, consider whether you have a history of skin breakdowns. Consider whether you may get a urinary tract infection and the possibility of sepsis because you don't have assistance. The goal of a social admission is to help you avoid serious consequences to your health. You are best able to make these decisions based on your personal experience. If you have questions, contact your healthcare provider.

Then you can make a thoughtful decision about how long you can manage without formal assistance, and when you might need to go to the hospital. This is an individual decision based on your own risk factors, but it is important to seek support BEFORE you get sick. For example, a urinary tract infection from not having personal assistance to clean you up could impact your thinking or ability to get needed medical attention. That would put you at serious risk of life-threatening harm.

I DON'T WANT TO GO TO A NURSING FACILITY AND LOSE MY FREEDOM.

We understand that. Neither do we. That's why we are writing this guide.

We all know that institutionalization is the first thing many professionals think of when there are problems with community-based services, but as a Disabled individual protected by the Americans with Disabilities Act, you have a right to receive services and supports in the Most Integrated Setting and avoid unwanted institutionalization. In this case, you are being responsible and arranging

alternative services meet your needs. If you don't plan ahead and get sick, your risk of institutionalization increases dramatically. In that case, professionals will be able to make the case that you didn't take care of yourself.

INITIAL NOTIFICATIONS

Start by notifying your CDPAP funder – either a managed care organization or a social service district – and your doctor about your plan. If you have a service coordinator or care manager through another system, notify them as well.

Care management is more than authorizing services. During the transition your funder was responsible for assisting you in making a successful transition. Although they were responsible for assisting you, it is likely that you didn't even get one call from them. Frankly, we aren't aware of anyone whose care manager through managed care or a social services district worked with them to transition to PPL, but they are being paid to do this work for you.

1. Call your funder and ask to speak to your care manager or worker. Explain the situation and tell them that there is a gap in your CDPAP services. Because the state's press releases have minimized the difficulties people have had enrolling, your care manager may be surprised that you are going without services. They may challenge you or even blame you for the problem, particularly if you are one of the first calls they get. Remain calm and let them know what you have done to try and enroll. Highlight any barriers you have experienced, including not getting callbacks.
2. Ask them if they have other supports that can assist you during any gaps. For example, they may have contracts with Certified Home Health Agencies, Licensed Home Care Services Agencies, or Private Duty Nurses who can fill in any gaps, but it's important to understand the limitations of these services.
 - *Traditional home care does not have a sufficient workforce* to meet people's needs and often won't accept "must-fill" consumers – Disabled people who rely on the agency to meet all of their needs because they don't have family who are informal supports. That's how many Disabled people have ended up using CDPAP.

- *It may not be legal for other services to assist you.* CDPAP allows you to get assistance with health-related tasks, including assistance with ventilators and feeding tubes. Most traditional home care services can't do those tasks. Even giving Disabled people basic over-the-counter medications may not be permitted. These tasks may be done by a nurse. Although Private Duty Nursing is included as a Medicaid service, functionally almost no one ever gets it because there is a shortage of nurses and managed care just won't pay enough for this service. This is another reason people use CDPAP.
3. If other options are not a viable plan, let them know that you may need to do a social admission to the hospital to address any gaps in your services and ask them to ensure that they have arranged for Medicaid transportation services to get you – and your mobility device – to medical appointments. You probably know the required lead time needed for a ride, but if you don't determine that amount of time so you can provide sufficient notice.
 4. Tell your care manager that you want your Person Centered Plan goals to be modified to include "Ensuring your health and safety while you make the transition to the Statewide Fiscal Intermediary." This is much more important than it seems. Making this a part of your plan requires them to take action on it. As part of this goal, tell them you may need them to get information for you from PPL or work with PPL to enroll you and/or your attendants. Let them know that you are considering a social admission to the hospital.

If you can't reach anyone, leave a detailed message. Let them know what is going on and ask for a return call. If you don't get a callback within a few hours, call and ask to speak to the supervisor. Keep doing this until you reach someone.

Document your call(s) to the funder. Notifying your care manager is important because it puts them on notice that you do not have the services you need to remain safe and independent in the community. Document when you called and who you spoke with. Your documentation doesn't need to be formal, but it is important information. If you don't have another option, call us at RCIL (585-442-6470) and we will document it for you.

Contact the office of your primary care physician. Your primary care physician is responsible for your medical care and can facilitate your social admission to the hospital if and when it is needed. When you call the office explain:

- You have successfully used CDPAP, but that the state's changes have interrupted your services.
- You have contacted your care coordinator at the managed care organization or social services district, and they are trying to assist you or are unable to assist you in getting the services you need at this time.
- If needed, explain how you have assessed your risk and let them know that you will be contacting them when you need to go to the hospital.
- Tell them that you may need to go to the hospital as a social admission to fill in gaps in your services.
- Make sure your medication list is correct.
- Have them include information about supplements or over-the-counter medications you may be taking. If you are using recreational cannabis to handle a medical condition – like stress, anxiety, or some other medical need – have them document this as well.
- Let them know you will need them to call the hospital when you need to go and (unless you have access to a vehicle) you will be using Medicaid transportation for the trip to avoid tying up an ambulance and so you have your mobility device at the hospital.
- Finally, explain any disability accommodations you might need at the hospital – such as an adapted call button, pressure-relieving mattress, or specific equipment for transferring – so the doctor can communicate that to the hospital when you go.

Identify a support person to keep track of you. It can be easy for Disabled people to get “lost” in the medical system. This person doesn't need to come to the hospital, but should be someone you speak with everyday so they know how you are doing, and can contact an advocate if needed. This person is your safety net to make sure you get back home. If you don't have someone, call your local Independent Living Center – or us at 585-442-6470

PREPARING FOR YOUR SOCIAL ADMISSION

First, you will need to arrange for someone to handle any issues at your house, like getting the mail or checking to make sure everything is OK. That includes taking care of any pets. Even though you are taking responsibility for your health,

this will be stressful. Knowing that your home and pets are being cared for will make this easier. We have all been in this situation and know this.

Make sure you have your essential documents. Generally, when people go to the hospital, it's under confusing circumstances. You have at least some time to prepare. Make sure you have your identification and insurance cards. You may also need the following documents, particularly if you may be going to a hospital outside your primary network:

- List of medications (with doses and schedule)
- Health Care Proxy
- Power of attorney or guardianship papers (if applicable)
- Emergency contact info
- List of allergies or special needs
- Medical history (e.g. recent reports, care plans)
- Names and contact information for your care manager or service coordinator

You will be working with hospital staff who are unfamiliar with your routine. Bring your care plan and any training materials you use for new attendants.

Gather any disability-specific items you will need at the hospital. The hospital should have most of what you need, but you may need to bring personal communication devices, specialty positioning supports, or other unique equipment such as specialty adapted utensils and hydration aids. Bring some "specialty" supplies – like ostomy bags – because the hospital is unlikely to have the ones you use. You should have your personal mobility device, so don't forget the charger if you need it!

Pack a small bag, including 1) personal care items or toiletries (toothbrush, toothpaste, deodorant, electric razor, shampoo, brush or comb), 2) comfortable clothes, and an item that gives you some comfort.

You aren't sick. It will be boring. If you generally are up in your wheelchair during the day, you can do that while in the hospital. You can bring a few things to keep occupied:

- A couple of books or magazines
- Laptop or tablet with charging cable
- Cell phone with charger (10 foot length is best)
- Headphones

- Earplugs or eye mask (if they will help you sleep)
- Spending money for snacks and such

Bring what you really need. There isn't a lot of room and things get lost at the hospital. Try not to bring anything you would be devastated to lose.

GOING TO THE HOSPITAL

Pick a time that makes sense for you. We've all gone to the Emergency Room late at night. It's chaotic. For a social admission, go during the day.

Recognize the risk of sitting up in your wheelchair without a break, sitting in feces, or getting impacted. These are all really bad. Try to go BEFORE these become an issue that impacts your health.

Consider your medication schedule. This won't be fast. You will need to account for the time to get there and get admitted before you will get any medications from them. You may want to bring your meds with you in case you end up waiting a long time and need to take them.

Call your doctor to have them notify the hospital that you are coming and (if necessary) arrange Medicaid transportation to the hospital. Medicaid transportation should be arranged to go to the hospital. Do not specify that you will be going to the emergency room because then you will be taken by stretcher on an ambulance. Instead, say that you have an appointment. If necessary, remind them that you need your mobility device. This is also a responsible choice. You don't want to tie up an ambulance that someone else needs to get emergency medical care.

Call your service coordinator and let them know you are going to the hospital.

Have someone you trust – and enjoy being with – meet you at the hospital or go there with you. It is helpful to have someone to carry things for you, assist at the hospital, and keep you company while you wait. If you are friends with someone who has OI – osteogenesis imperfecta or brittle bones – they likely have a lot of experience in the Emergency Room and tend to be a lot of fun. We know it's a stereotype, but we also know it's kinda true.

Hospital staff may question why someone is able to wait with you, but not provide your personal assistance at home. Interrupt the hospital staff and politely indicate that you don't want to discuss other people's health and personal information.

HOSPITAL INTAKE

Your doctor should have called the hospital to let them know you are coming. This should make the process smoother. Although they may suggest you look at nursing facility placement, you can tell them:

- I have lived successfully in the community using Consumer Directed Personal Assistance Services for ___ years, but because of state policy changes and issues with the new fiscal intermediary, you don't have the assistance you need right now. This temporary gap in services is not my fault.
- I have a right to receive services in the community under the Supreme Court's *Olmstead* decision and forcing me into an institution would be a violation of my rights.
- Even if I was considering placement in a nursing facility, that takes time and I have immediate unmet personal assistance needs.
- Going into a nursing facility would potentially impact my personal assistance services, financial benefits, and housing which would put me at significant risk of permanently losing my freedom which is unacceptable to me and – again – a violation of my rights.
- I am not able to go home because – without CDPAP services – it isn't safe for me. Then explain why going without services would be unsafe for you. (infection, fall, etc.)

If the hospital argues that they don't provide social admissions, give them the contact information for your doctor, CDPAP funder, and service coordinator (if applicable). Let the professionals argue about it. Hang out with your friend.

You can also engage an advocate:

- Ask to speak to the hospital's patient advocate or patient representative
- Call the State Senior Action Council's Hotline at 800-333-4374
- Call Disability Rights New York at 800-993-8982
- Call the Regional Center for Independent Living at 585-442-6470

After you have been admitted, ask to speak with the social worker. The hospital wants you out so that sick people can use the emergency room. When you meet with the hospital social worker, provide them with a copy of the contact information for your care manager so they can work with your care manager to get your services set up through PPL. You should move to the top of their list.

DURING YOUR STAY AT THE HOSPITAL

This is when the professionals should be working together to help get you home. The hospital staff can be your best ally in getting your services set up. They will be able to get through to people who would otherwise just ignore you.

Your care manager may need to assist with recruiting workers if your workers won't continue with you at PPL. This is part of their responsibility as your care manager and consistent with the goals in your Person Centered Plan. If the care manager at your managed care organization is not helping you, you can contact the Independent Consumer Advocacy Network at 844-614-8800.

If you want, do some advocacy.

Call your state representatives. Advocates told state policy makers Disabled people who didn't have services would go to the hospital. They didn't believe us. The fact that you are in the hospital demonstrates the disregard for you and your life.

Share your story with the media if you feel comfortable. You can share your story on social media, connect with other advocates, and even give an interview to press (if you want). For assistance, contact:

- Caring Majority Rising at 571-232-0872
- Consumer Directed Action of NYS at 518-813-9537

Keep your family and friends updated. The people who care about you will be worried. Let them know how you are doing. Folks can visit you and support you in other ways. They can always bring snacks!

GOING HOME

Confirm that your services are in place. Your care manager at the funder (or waiver service coordinator) should be working to make sure your workers are enrolled and payroll ready. Get confirmation that everything is in place before you leave the hospital.

The hospital social worker should coordinate your trip home. They want to free up that bed.

Review your discharge papers. In our experience, hospitals have told Disabled people that they were going home and then the person was taken to a nursing facility. Really. That has happened. The discharge paperwork should clearly indicate what the discharge plan is. If not, make sure it does. Read it and make sure you agree to the plan BEFORE you sign anything. If you can, have a friend or advocate be with you when reviewing the paperwork. They can be a support and a witness.

Confirm that the address with the transportation provider BEFORE getting into the vehicle. We know it may seem a bit “over the top” but we have had some bad experiences with this.

GOING BACK IF NEEDED

The state has eliminated virtually all of the support folks have had from their local fiscal intermediary. PPL is not contracted to assist you in the same way. If you have additional problems with your services and gaps in your services, go back to the beginning and use this guide. Stay safe and stay alive. You are important to us.

You also have your care manager at your funder who is responsible for your care. You can add and change goals on your Person Centered Plan and use them as a resource in navigating the system and getting services in place. Your goals can be more than just personal assistance. Get your money’s worth.

If you need peer support or individual advocacy, you can always contact your local independent living center or the Regional Center for Independent Living at 585-442-6470. We may not be local, but we can connect you with local resources and we care.

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About RCIL

The Regional Center for Independent Living is a disability-led membership organization with over 5,500 members throughout New York State. The majority of our members rely on Medicaid Home and Community Based Services or home care services, and we estimate that more than 4,200 of our members use CDPAP services to remain in the community. RCIL is one of the oldest Centers for Independent Living in the country and traces its history to September 1966 when a group of Disabled students protested to make the State University of New York system accessible to people with disabilities during the New York State Republican Convention which was being held in Rochester, NY. This was one of the first – if not the first – disability rights protest of the modern disability rights movement.